



Measuring the Planning Process: Review of Existing Measures

Lynn Martin, PhD

Department of Health Sciences, Lakehead University

Hélène Ouellette-Kuntz, MSc

Department of Community Health & Epidemiology, Queen's University

Virginie Cobigo, PhD

School of Nursing Sciences, University of East Anglia

Melody Ashworth PhD Candidate

University of Toronto - OISE

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Enhanced social inclusion, choice and independence are outcomes central to recently passed legislation in Ontario – The Social Inclusion Act. The goal of MAPS is to achieve a consensus of what is meant by social inclusion and choice and how to best capture information about these outcomes.

MAPS is a provincial interdisciplinary team of researchers working with individuals with intellectual/developmental disabilities, their families, service providers, government representatives and researchers in other provinces and countries. The research team is led by Professor H  l  ne Ouellette-Kuntz (Departments of Community Health & Epidemiology and Psychiatry, Queen's University) and is composed of Dr. Virginie Cobigo (School of Nursing Sciences, University of East Anglia), Dr. Robert Hickey (School of Policy Studies, Queen's University), Dr. Rosemary Lysaght (School of Rehabilitation Therapy, Queen's University), Dr. Yona Lunsky (Department of Psychiatry, University of Toronto, and Research Head of the Dual Diagnosis Program at the Centre for Addiction and Mental Health), and Dr. Lynn Martin (Department of Health Sciences, Lakehead University).

Contact Information:
MAPS
191 Portsmouth Avenue
Kingston, Ontario, CANADA, K7M 8A6
Phone: 613-548-4417 x. 1198
Email: admin@mapsresearch.ca
www.mapsresearch.ca

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Executive Summary

Planning that is based on what is important and meaningful to the individual has become common practice in the developmental services sector in Ontario and elsewhere. This approach embraces the principles of social inclusion and choice in its practice, and also aims to have an impact on these. Person-directed planning (PDP) goes a step further by emphasizing that the person with an intellectual/developmental disability is not only at the centre of planning, but is the one *driving* planning.

The Minister's regulation on Quality Assurance Measures under the Services and Supports to Promote the Social Inclusion of Persons with Developmental Disabilities Act (2008) calls for every service agency to promote social inclusion and choice. PDP is an important means to achieving these outcomes. However, in spite of being adopted by many jurisdictions worldwide, the evidence outlining the dimensions and effectiveness of PDP is still limited. As a consequence, there is no real way to determine and measure whether service providers are engaging in PDP, or whether they are adhering to its principles. In a climate where funds are limited and resources are scarce, the ability to demonstrate the effectiveness of services becomes all the more important.

The goal of the PDP study is to fill the knowledge gap and to support the developmental services sector in its move toward PDP by developing an understanding of PDP and identifying a set of relevant indicators to measure its effectiveness. To this end, a set of core elements of PDP practice were identified in the first year of the project.

In the second year of the study, we conducted a review of academic literature for measures of PDP. A total of 53 unique references were identified across the multiple databases used. A review of titles and abstracts permitted the elimination of 33 references that not directly related to the measurement of PDP practice. The remaining 20 references were read and reviewed. The more in-depth review of articles led us to realize that only four of the papers actually reported on the measurement of planning practices. A number of papers identified discussed the notions of measurement related to PDP practice without providing information on measures.

Five scales were identified that measured PDP, and these tended to focus on quantitative, self-report measures of staff, did not involve persons supported or their natural supports in the evaluation of PDP, and had questionable applicability to persons with varying abilities, races, ethnicities or geography. Some qualitative approaches were identified, but these studies did not provide enough detail to fully understand the measurement process.

We also found that the core elements of PDP proposed through our work to date were covered in the content of the scales, though no single scale addressed all of our proposed elements. Most scales have concentrated on a particular aspect of PDP practice (e.g., team functioning).

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To our knowledge, the MAPS project is alone in its attempt to fully measure PDP practice, with its various complexities and multiple dimensions.

The literature review failed to identify the existence of a ‘gold standard’ scale to measure PDP. In addition to their limitations, none of the scales that were identified appear to be in use in the field, or by anyone other than the researchers who developed them. For this reason, we are unable to recommend the use of an existing scale to measure PDP practice across the province.

While the proposed core elements of PDP practice identified through our work largely appear to contain the necessary content, they should not be taken to represent a “checklist” for quality PDP practice. A checklist approach to the measurement of the quality of PDP is not appropriate, mainly because adherence to the underlying principles of PDP is but one of the factors that need to be in place for PDP to occur – sufficient and appropriate funding and well-trained staff are also instrumental (Joseph Rowntree Foundation, 2006). For this reason, the core elements of PDP practice represent only a part of the picture, and cannot on their own adequately described the quality of PDP occurring within the developmental services sector.

In developing indicators relevant to the adherence to the core elements of PDP, it will be important to include a diversity of methods of data collection (i.e., qualitative and quantitative), from various informants (i.e., person supported, natural supports, planner/facilitator, and staff involved in planning) to measure both the concrete aspects (i.e., person and natural supports are involved; plan focuses on the person’s strengths, abilities, and aspirations) as well as the complex, ill-defined aspects (i.e., trust, meaningful choice) of planning in a way that is both practical and meaningful to those involved.

In the final year of the PDP project, such indicators will be proposed. The PDP team will work closely with the other MAPS researchers to identify staff- and system-related indicators that will be key to completing the ‘picture’ of PDP and to measuring its quality.

Introduction

*“People come to life when they make contact with someone who works actively and faithfully to understand what they want to say.”
(O’Brien & O’Brien, 2007, p15)*

The Minister's regulation on Quality Assurance Measures under the Services and Supports to Promote the Social Inclusion of Persons with Developmental Disabilities Act (2008) calls for every service agency to promote social inclusion, choice, and independence. Person-directed planning (PDP) is central to achieving these outcomes. In spite of being adopted by many jurisdictions, evidence outlining the dimensions and effectiveness of PDP remains limited. As a consequence, there is no real way to measure whether service providers are engaging in PDP or adhering to its principles. In a climate where funds are limited and resources are scarce, the ability to demonstrate the effectiveness of services becomes all the more important.

Monitoring the fidelity of PDP practice – i.e., the extent to which it reflects the values and principles on which it is based is crucial because how PDP is conducted will impact the outcomes of planning. Without information on or measurement of planning, it is impossible to draw valid conclusions about the relationship between PDP and its outcomes – another area in which there is limited empirical data. Further, measurement will help to identify which components of PDP are more critical than others for achieving outcomes. For example, continuous commitment to reviewing the plan and progress toward goals may be more critical to achieving outcomes than how involved the person with intellectual/developmental disability (I/DD) was in planning the logistics of the meeting.

Based on a review of the literature completed in the first year of the study, we developed a set of 14 core elements of PDP practice that will be useful for evaluating the quality of PDP practice (Martin, Ouellette-Kuntz, Cobigo, Lunskey, Brown & Ashworth, 2011); see Table 1. The proposed core elements reflect the various dimensions of the planning process, including the organization of the planning meeting, the planning meeting itself, the resulting plan, and post-planning meeting follow-up or review.

In the second year of the PDP project, the focus has been on understanding the planning landscape in Ontario and the lived planning experiences of persons involved in planning; identification of potential indicators related to PDP; and the availability and ease of obtaining data related to these indicators in Ontario. The purpose of this report is to provide a summary of findings related to the identification of potential indicators of PDP. In particular, it reviews the existing methods for measuring PDP. These findings will inform the development of indicators to evaluate PDP within the context of a Multidimensional Assessment of Providers and Systems (MAPS) for Developmental Services in Ontario.

Table 1: Proposed Core Elements of PDP Practice

Core elements
1) The person is involved in selecting the timing and location of the meeting
2) The person chooses who is involved
3) The person is involved in discussions
4) The person has the opportunity to make meaningful choices
5) The person's natural supports are encouraged to participate in discussions
6) There is trust among the members of the planning team
7) The team works collaboratively and with respect
8) Focuses on the person's strengths, abilities, and aspirations
9) Identifies clear actions to achieve the goals in the plan
10) Identifies supports within and beyond those of the provider agency that are needed to achieve the goals in the plan
11) The person's services, supports, and day-to-day activities are adapted to ensure that they are in sync with the goals identified in the plan
12) Periodic evaluation of actions and outcomes
13) Ongoing commitment to revisiting actions and outcomes
14) The person is happy or satisfied with progress made toward identified goals

Methods

A systematic search of peer-reviewed literature published in English between 2000 and 2011 was conducted in the spring and summer of 2011 using the following databases: MEDLINE, Social Sciences Abstracts, PsycInfo, ERIC, FRANCIS, and Social Services Abstracts.

The search strategy included three lines of search terms:

- 1) 'person-centered planning', OR 'person centered planning', OR 'person-centred planning', OR 'person centred planning', OR 'person-directed planning', OR 'person directed planning',
AND
- 2) intellectual disabilit*, OR developmental disability*, OR mental retard*, OR learning disability*, OR cognitive disability*
AND
- 3) effective*, OR eval*, OR evidence, OR process, OR best practice, OR indicator

A total of 75 references were identified across the databases. After removal of duplicated materials, 53 references were saved. Titles and abstracts were reviewed, and this permitted the elimination of 33 references not directly related to the measurement of PDP (e.g., deleted those related to measuring PDP outcomes). The remaining 20 references were read and reviewed, and a table was created that contains the following information for each of the 20 articles (see Appendix A):

- Reference for the article
- Country in which the study was conducted
- Objectives
- Methods (e.g., design, sample size and characteristics, procedure)
- Measures
- Findings
- Limitations.

Based on the in-depth review, it was found that, in reality, only four of the articles reported on the actual measurement of PDP. A large proportion of papers dealt with the ideological opposition or support to measuring PDP.

As the review focused on the peer-reviewed literature, approaches to measuring PDP that are not currently documented in the scientific literature are not be included. Also, two PDP process scales that were developed prior to 2000 were identified in the review; these were included in the review because they formed the basis of a third scale developed post 2000.

Results

Identified Measures

Only a handful of scales have been developed and used to measure PDP. Information on the five identified scales is provided here.

A. ***The Indicators of Principles Scale*** (Schwartz, Jacobson, Rossi, Warren & Holburn, 1996 as cited in Holburn, Jacobson, Vietze, Schwartz, & Sersen, 2000) is a 25-item scale designed to assess adherence to eight features of planning:

- 1) services and supports are derived from the person's preferences,
- 2) the person and important others are involved in planning,
- 3) the person makes choices and decisions based on his/her previous experiences,
- 4) activities and services foster inclusion, respect, and relationships,
- 5) the person uses natural community supports,
- 6) planning is collaborative and ongoing,
- 7) opportunities, experiences, and flexibility are maximized, and
- 8) the person is satisfied with services and supports.

The response formats for the 25 multiple choice items are varied, and include measures of frequency (i.e., "almost always, usually, sometimes, seldom, and almost never" or "daily, weekly, monthly, semi-annually, and less than semi-annually"), agreement (i.e., I agree strongly, I agree, I agree somewhat, I disagree, and I disagree strongly), and number of elements that are part of the individual planning process (i.e., all three, two, one, and none).

There is no mention of ranges of scores, or meaning or interpretation of scores for this scale. Further, there is no evidence of psychometric testing of the instrument's properties (i.e., reliability, validity).

B. ***The Personal Futures Planning Indicators*** (Mount & Holburn, 1996 as cited in Holburn et al., 2000) consists of 12 items that measures the presence or absence of 12 features of planning:

- 1) a desire for change by at least one team member,
- 2) a skilled facilitator,
- 3) a positive view of the focus person's capacities and talents,
- 4) a team member who is committed to act on behalf of the focus person in bringing dreams and goals to reality (i.e., committed champion),
- 5) a personal vision for a rich life in the community,
- 6) a team member who knows the community and creates consumer opportunities there (i.e., community builder),
- 7) connections to a wider community (e.g., through team members involvement in various community organizations),

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- 8) an agency committed to changing existing organizational policies for individualized supports,
- 9) access to decision makers at various levels,
- 10) flexible resources for personal support,
- 11) a diverse group of voluntary team members (i.e., the support circle) and
- 12) a productive ongoing process to meet and review progress and to follow up on goals.

Scores on the scale may range from 0 to 12. In their paper, the authors do not offer information on the interpretation of scores, nor on the instrument's psychometric properties (i.e., reliability, validity).

C. **The Process Index** (Holburn et al., 2000) is a 20-item scale based on the features identified in both the Indicators of Principles Scale (10 items with variable response options ranging from 3 to 5 options) and the Personal Futures Planning Indicators (10 items with two response options) described above. Responses from the two different instruments were summed to derive 6 scale scores and 1 index score; items were weighted to give an equal contribution to each scale. Therefore, the Process Index captures information on six scales which are the overarching components of planning, including:

- 1) presence of strategic roles (5 items),
- 2) personal relationship with focus person (2 items),
- 3) desire for change (2 items),
- 4) creation of a personalized vision (4 items),
- 5) commitment to planning and follow-up (5 items) and
- 6) flexible funding/resources (2 items).

Scores for each of the 6 scales are variable depending on the number of items for that particular scale. With regard to the overall Process Index, higher scores indicate more desirable outcomes.

The psychometric properties of the Process Index have been tested. A strong positive association was reported between it and the author's companion *Outcome Index* ($r = .69, p < .01$; range $r = .40 - .79, p < .01$) (Holburn et al., 2000).

D. **Assessment of PCP Facilitation Integrity** (Holburn, Gordon, & Vietze, 2007) is a scale used to determine facilitator adherence to 22 features of planning, including those related to meeting logistics (6 items); the attitude, skills and duties the facilitator (15 items); and written documentation (1 item) [note: these groupings are proposed by the MAPS researchers, not the developers of the scale]. Items are rated using the following response set: yes, no, or not applicable.

An independent observer, who is not part of the planning team, watches the meeting unfold and then completes the assessment immediately following the meeting. Each item is rated using yes, no, or not applicable. The results of this assessment are intended to be

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shared as feedback to the planning facilitator as well as the planning team, if desired, to solicit discussions to maintain and/or improve the quality of planning.

No studies were identified that examined the psychometric properties of this instrument (i.e., validity and reliability).

E. **Assessment of PCP Team Integrity** (Holburn, Gordon, & Vietze, 2007) is comprised of 12 items that reflect team member interaction at a planning meeting:

- 1) used everyday language during the meeting,
- 2) viewed problems as opportunities for lifestyle improvements,
- 3) suggested solutions to problems,
- 4) were respectful of the person,
- 5) listened attentively to other team members,
- 6) considered others' options,
- 7) were not hindered in problem solving by an absence of important team members,
- 8) promoted decision making by the person,
- 9) honored the person's preferences and choices,
- 10) kept discussions centered on the person rather than each other or the agency,
- 11) were not negative in their expectations of the person, and
- 12) followed through with commitments made in previous meeting.

An independent observer, who is not part of the planning team, evaluates the degree to which each of the 12 indicators was observed during the planning meeting using a 5-point response scale (e.g., no team members, some team members, most team members, all team members, or not applicable).

No studies were identified that examined the psychometric properties of this instrument (i.e., validity and reliability).

Other Measures

The review also identified the **Five Dimensions Tool** (Smith, 2007), which measures five dimensions of planning, including: (1) uniqueness and diversity; (2) equal power; (3) right relationship; (4) developing, learning, and growing; and (5) usefulness and relevance. However, this tool targets organizations not persons with IDD or their planning teams, and is designed for use during the implementation of PCP in the organization. How these five dimensions are measured remains unclear, as no information on data collection or procedures are provided by the author.

The **5-Feature Framework to PCP** (Cook & Abraham, 2007) seeks to qualitatively measure whether five key principles of PCP are adhered to, including: (1) the person is at the centre; (2) family members and friends are full partners; (3) planning is reflective of the person's capacities and what is important to him/her; (4) planning recognizes the person's rights and builds a shared commitment to action; and (5) planning leads to ongoing listening, learning, and action.

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It appears, that the information is gathered during an unstructured interview with team members – though not the person supported, where very broad questions about planning are asked (e.g., “What helped or hindered the person being at the centre of PCP?”). No concrete details related to measurement are provided by the authors.

Linking Identified Tools to the Proposed Core Elements

The items in the identified measures were then linked to the identified 14 core elements of PDP practice previously identified by the MAPS team (see Appendix B); Table 1 below summarizes these results.

The findings revealed that all 5 scales measured whether there was a focus on the person’s strengths, abilities, and aspirations, and whether there was an ongoing commitment to revisiting actions and outcomes. Four of the five scales measured whether the person is involved in discussions; the person chooses who is involved in the meeting; the natural supports are encouraged to participate in discussions; the team works collaboratively and with respect; and the actions and outcomes are periodically evaluated. Three scales measured whether the person has the opportunity to make meaningful choices; the plan identifies clear actions to achieve goals; and the plan identifies supports needed to achieve goals. Two scales measured whether the person is happy or satisfied with progress made toward goals. One scale measured whether the person is involved in selecting the time and location of the meeting and if there was trust among the members of the planning team.

Table 2: Number of Scales that Cover the Proposed Core Elements of PDP

Core elements	Number of scales
The person is involved in selecting the timing & location of the meeting	1/5
The person chooses who is involved	4/5
The person is involved in discussions	4/5
The person has the opportunity to make meaningful choices	3/5
The person’s natural supports are encouraged to participate in discussions	4/5
There is trust among the members of the planning team	1/5
The team works collaboratively and with respect	4/5
Focuses on the person’s strengths, abilities, and aspirations	5/5
Identifies clear actions to achieve the goals in the plan	3/5
Identifies supports within and beyond those of the provider agency that are needed to achieve the goals in the plan	3/5
The person’s services, supports, and day-to-day activities are adapted to ensure that they are in sync with the goals identified in the plan	3/5
Periodic evaluation of actions and outcomes	4/5
Ongoing commitment to revisiting actions and outcomes	5/5
The person is happy/satisfied with progress made toward identified goals	2/5

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We also identified aspects of planning currently measured in existing scales that are not captured in the previously proposed core elements of PDP. These include:

- assisting the person to experience and understand the alternatives before making choices (Indicators of Principles Scale),
- the person has appropriate control over economic resources and opportunities to spend his or her own money (Indicators of Principles Scale),
- having a member of the planning team who is actively involved in the community and whose role is to make connections to community resources to respond to the person's individual needs (Personal Futures Planning Indicators), and
- competency or skills of the planning facilitator (Personal Futures Planning Indicators and Facilitation Integrity measures).

The literature review also identified elements of planning that should be measured, but are not part of existing scales or the proposed core elements of PDP, such as:

- whether or not the planning facilitator met with the person prior to the meeting to establish a relationship (Callicott, 2003; Cook & Abraham, 2007),
- preparing the person and team members for the meeting (Claes, VanHove, Vandevelde, van Loon, & Schallock, 2010; Lotan & Ells, 2010),
- person is introduced to communication tools used in PCP (Cook & Abraham, 2007),
- team has set ground rules for the meeting (Callicott, 2003),
- team listens to the person without judgement (Callicott, 2003),
- plan identifies barriers to the person's goals and ways around them (Lotan & Ells, 2010),
- follow-up with the person to review what did or did not go well (Lotan & Ells, 2010) and
- plan is written in a way that is accessible to the person (Cook & Abraham, 2007).

Discussion

Identified Measures

While there is a need to verify the integrity of PDP to validate its relationship to desired outcomes, very little work has been done in this area. In fact, most published studies concerning the measurement of PDP have involved one researcher, namely Dr. Steve Holburn from the United States. According to Holburn and colleagues (2000), there are a variety of reasons why interest and progress in the measurement of PDP is lacking to date – for example, the need for PDP to remain non-standardized and adaptable to the person’s changing needs and circumstances; PDP’s complexity (i.e., multiple components); the inclusion of ill-defined concepts (e.g., mindful engagement, trust among team members); and the ambiguity and overlap between what is part of the *process* and what is an *outcome* of the planning (e.g., choice – choice making is a part of the planning, but increased choice is also an outcome). As there is no single method of doing PDP, its measurement tends to focus on the extent to which it reflects the core values of PDP.

Among the measures that exist, few offer concrete details on scoring and interpretation of scores, and even fewer have undergone rigorous psychometric testing. The reliability and validity of these measures is therefore questionable or unknown. None of the scales reviewed presented a “minimum threshold” that can be used to determine not only whether quality PDP is taking place, but whether PDP is even taking place at all (Holburn et al., 2000). For example, how few elements need to be followed to be conducting quality PDP? Further, some components of PDP may be more crucial or salient to promoting positive life outcomes for persons supported compared to others (e.g., commitment to actions and goals versus attending the planning meeting itself). When psychometric testing has been done (see results of factor analysis published by Holburn et al., 2000), the results reveal considerable overlap between the *process* and *outcome* variables. This may highlight the need for additional refinement of scales, or more likely, provide empirical support related the conceptual conundrum surrounding the difficulty of separating the inputs (i.e., process) and outputs (i.e., outcomes) of PDP (Holburn et al., 2000). Further, there is no information on the extent to which scores on the instrument are actually related to desirable outcomes of PDP, if at all. For example, is there a certain scale score that indicates increased likelihood of achieving goals?

The largest criticism of the literature is that the scales and studies to date do not appear to involve the person supported in the assessment of PDP, and they often don’t include family members or advocates, even in cases where the person is unable to communicate responses (Cook & Abraham, 2007). When they are involved, persons supported are asked to identify their dreams, but this does not provide information on how PDP practices supported them to achieve those dreams. Given that the tools do not seem to involve the person supported in the evaluation of planning, they also don’t bring to light the unique ways in which information can be solicited from individuals with varying levels of cognitive and communication skills. For example, should proxy responses be used in instances where the person is unable – or doesn’t

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wish to participate in the evaluation of planning, or should the focus be on the responses of other team members?

The scientific literature has also focused on quantitative measures (Halle & Lowrey, 2002). However, qualitative methods (e.g., grounded theory, case studies) may also be useful. Measurement has mostly relied on self-report questionnaires completed by professionals (e.g., planning facilitators, paid support staff, managers) to inform on how well they implemented the particular components of PDP. The use of self-reported staff measures are problematic in the assessment of the integrity of PDP as ratings are unrelated to observational measures of the process and may inaccurately represent the true level of process integrity (Gresham, 2009). Direct observation of the planning process may also be useful to evaluate the integrity of PDP practice, as it relies on the ratings of someone independent of planning. One caveat of the direct observation method in assessing integrity is that it may produce reactivity among team members and as such they may be more likely to adhere to PDP steps in the presence of an evaluator than when one is absent. As a consequence, some would argue that multiple methods of measuring the integrity of PDP are needed (Gresham, 2009) – including the perspective of the person with IDD and his/her natural supports.

The review also highlighted that most studies on the measurement of PDP have been conducted in the United States with little diversity in the samples studied. More information is needed on the extent to which existing scales measuring PDP apply to persons with differing abilities (cognitive, communication), races, ethnicities, languages, or geography.

In summary, given the limited evidence of psychometric properties, failure to take into account the perspective of persons with IDD and their natural supports, and focus on certain aspects of PDP, we are unable to recommend the use of an existing scale in the measurement of PDP practice. Further work is needed to develop a measure of PDP that examines the practice in its entirety, and uses a diversity of methods, perspectives, and informants to gather information.

Linking Identified Tools to the Proposed Core Elements of PDP Practice

In doing this review, we found that the previously proposed core elements have been addressed in the existing measures of PDP, though no single instrument comprehensively covers all the core elements we have proposed. Again, the identified scales measure unique aspects of PDP (e.g., facilitator's skills, team skills, etc.) instead of its multiple dimensions.

We also identified components of PDP covered in existing measures that were not part of our proposed core elements, as well as some that have been recommended but are not captured in existing scales or the proposed core elements. These will certainly be considered in the refinement and finalization of a framework for understanding PDP and generation of indicators for monitoring the quality of PDP. The input of key stakeholders will also be sought.

Conclusion

In reviewing how PDP is currently measured, we found that very little work has been done in this area to date. Much of what has been done focuses on philosophical or ideological arguments cautioning researchers about measuring PDP or questioning whether it is necessary to measure it at all. Only five scales were identified that measured PDP, and a single researcher was associated with the development of all of these. Existing scales have focused on quantitative, self-report measures of formal support (e.g., staff), and have not involved with IDD or their natural supports in the evaluation of PDP. The degree to which these scales are relevant to persons with varying abilities, race, ethnicity, or geography (i.e., outside of US) is also unclear. We also found that the proposed core elements of PDP are covered in the content of the scales, though no single scale addressed all of our proposed elements. Most scales have concentrated on a particular aspect of PDP (e.g., team functioning). To our knowledge, the MAPS project is alone in its attempt to fully measure PDP, with its various complexities and multiple dimensions. Therefore, the literature review failed to identify the existence of a 'gold standard' scale to measure PDP. None of the scales that were identified appear to be in use in the field, or by anyone other than the researchers who developed them. For this reason, we are unable to recommend the use of an existing scale in the measurement of PDP.

While the proposed core elements of PDP practice identified through our work largely appear to contain the necessary content to evaluate PDP, they should not be taken to represent a "checklist" for quality PDP practice. A checklist approach to the measurement of the quality of PDP is not appropriate, mainly because adherence to the underlying principles of PDP is but one of the factors that need to be in place for PDP to occur – sufficient and appropriate funding, and well-trained staff are also instrumental (Joseph Rowntree Foundation, 2006). For this reason, the core elements of PDP practice represent only a part of the picture, and cannot on their own inform on the quality of PDP occurring within the developmental services sector.

In developing indicators for the measurement of PDP, it will be important to include a diversity of methods of data collection (i.e., qualitative and quantitative), from various informants (i.e., person supported, natural supports, planner/facilitator, and staff involved in planning), to measure both the concrete aspects (i.e., person and natural supports are involved; plan focuses on the person's strengths, abilities, and aspirations) as well as the complex, ill-defined aspects (i.e., trust, meaningful choice) of planning, in a way that is both practical and meaningful to those involved. In the final year of the study, such indicators will be recommended. The MAPS PDP team will also work closely with the other MAPS researchers to identify staff- and system-related indicators that will be key to completing the 'picture' of PDP and to measuring its quality.

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Appendix A: Summary of 20 Articles

1	Bui, Y.N. & Turnbull, A. (2003). East meets west: Analysis of person-centered planning in the context of Asian American values. <i>Education and Training in Developmental Disabilities</i> , 38(1), 18-31.
Country	United States
Objectives	Evaluate the extent to which core values of PCP are consistent with those held by Asian American subgroups, and the appropriateness of its use with Asian American families
Method	Synthesis of the literature on PCP and Asian American families who have children with disabilities
Measures	N/A
Findings	<ul style="list-style-type: none"> • Very little PCP research conducted with culturally and linguistically diverse individuals; none have been conducted with Asians • PCP and Asian culture have consistent values and features: (1) family harmony and extended family system is core to collaboration in PCP; (2) interdependence and family obligations is core to shared action in PCP; (3) respect for elders and authority figures is core to respecting experiential knowledge and utilizing supports and services in the community in PCP • PCP and Asian culture have conflicting values/barriers: (1) pride may conflict with PCP approach that uses outside help (disability is sometimes a source of embarrassment, shame and stigma to family, who are less likely to seek help or discuss family problems); (2) family's expectations for the child with a disability are low in terms of independence, productivity, and inclusion; (3) expectation for equal membership and participation in PCP conflicts with Asian values regarding gender roles and hierarchy within parent-child relationships; (4) PCP emphasis on individual preferences and desires is in contrast to the value of putting the group's needs before those of the individual; (5) PCP values the knowledge of non-professionals and family members conflicts with Asian's deference to professional knowledge • Recommend modifications to PCP to be more appropriate for Asian families around: (1) establishing relationships (e.g., choice between traditional services and PCP, consultation with oldest male in the family); (2) meeting logistics (e.g., arrange transportation, interpreter present); and (3) communication during meetings (e.g., address questions to main authority figure, pay attention to family's non-verbal cues, ensure privacy during meeting and confidentiality of discussions, give family privacy to make decisions)
Limitations	This paper does not measure the PCP process

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Martin, Ouellette-Kuntz, Cobigo and Ashworth, 2012

2	Callicott, K.J. (2003). Culturally sensitive collaboration within person-centered planning. Focus on Autism and Other Developmental Disabilities, 18(1), 60-68.
Country	United States
Objectives	Background and description of PCP process, components, and outcomes and how to be sensitive to differences in culture and language with the PCP process
Method	Synthesis of literature
Measures	N/A
Findings	<ul style="list-style-type: none"> • Essential processes in PCP include: (1) Mindset (i.e., focus on looking beyond what is available to what might be possible, having an open mind to all aspirations and desires of the focus individual); (2) Teaming (i.e., the focus person determines who will be part of this planning group, team members participate in response to an invitation and desire to help the focus person, team is positive and forward-looking); and (3) Facilitation (i.e., good interpersonal communication skills; listening, developing rapport, encouraging participation; develop a sense of trust and respect for all members of the team; and culturally sensitive communication style) • Essential components of PCP include (1) meeting logistics; (2) developing a personal profile for the individual; (3) constructing a future vision; (4) developing action sets; (5) providing support; and (6) evaluating and ongoing implementation. • PCP is culturally sensitive because it lets the focus individual and his/her family develop an individual plan based on their priorities and perceptions rather than those of agencies or schools.
Limitations	This paper does not measure the PCP process

Review of PDP Measures

Martin, Ouellette-Kuntz, Cobigo and Ashworth, 2012

3	Claes, Van Hove, Vandeveld, van Loon, & Schalock.(2010). Person-centered planning: Analysis of research and effectiveness. <i>Intellectual and Developmental Disabilities</i> , 48(6), 432-453.
Country	United States and Belgium
Objectives	Systematic literature review of the effectiveness of PCP
Method	<ul style="list-style-type: none"> • Systematic literature review of literature review between 1985 to January 2009 using Web of Science • Search terms used: person-centered planning and person-centred planning (when the term effectiveness was used it limited the number of hits substantially to only 15 articles. 108 potential articles were found. • Inclusion criteria: PCP was applied to persons with ID and researchers reported empirical findings on effectiveness • The methodological quality of each quantitative article was scored by 2 independent authors based on 16 criteria from the Downs and Black (1998) to evaluate the methodological quality and evidence base. • The methodological quality of each qualitative article was scored by 2 independent judges using the checklist and scoring system developed by Ceasario, Morin & Santa-Donato (2002) • Evaluation of outcome effectiveness was performed by 2 independent authors using a rating scale developed by Prout & Nowak-Drabik (2003). It is a 5-point scale. Each outcome in a study was evaluated. The average of the authors' ratings was used as the final score.
Measures	N/A
Findings	<ul style="list-style-type: none"> • 15 studies met the 2 selection criteria: 11 were quantitative and 4 were qualitative • Only 1 study reported on the assessment of the reliable implementation of PCP • Authors identified 5 difficulties/weaknesses associated with studies on PCP: (1) PCP reaches a minority of service users; (2) PCP is a paper exercise and not related to the lives of individuals with ID – plans are often not implemented, persons with ID do not understand their own PCP process; (3) flexible support that is needed to make PCP work is often not available in large service systems; (4) developing social networks that are needed for PCP are hard to establish; (5) too much optimism in PCP which results in unrealistic goals, failed outcomes, etc. • Conclude that PCP has moderate positive effects on the quality of life of persons with ID • Future research needs to examine how PCP produces results and for whom; look at valid implementation of PCP as well as its myriad of operationally defined outcomes.
Limitations	This paper does not measure the PCP process

Review of PDP Measures

Martin, Ouellette-Kuntz, Cobigo and Ashworth, 2012

4	Cook, T. & Abraham, L. (2007). An evaluation of the introduction of facilitated person-centred planning with people with learning disabilities leaving a hospital setting: Sharing the knowledge. <i>Tizard Learning Disability Review</i> , 12(4), 11-19.
Country	United Kingdom
Objectives	To determine whether the process of PCP being used was meeting the 'five key features of PCP' and to determine how to improve PCP
Method	Qualitative study: Face-to-face interviews and focus groups N=6 middle-aged or older males with LD/ID who were the first to receive a PCP
Measures	Qualitative data was analyzed using a "realist synthesis"; coded into pre-conceived themes
Findings	<ul style="list-style-type: none"> Was the person at the centre of PCP: all thought that the focus person was being recognized in the planning process; everyone disagreed about whether the person was at the centre of the plan-some just attended but did not participate. Others developed the plan; facilitator was good at mediating the varied views; concern that facilitator is influenced by organizational views and should therefore be an outside party; participants suggested that the facilitator get to know the focus person beforehand to better understand and represent their wishes more accurately; focus person may lack understanding or comprehension of what it means to have choice What hindered a person being at the centre of PCP in relation to their own plan: (1) Training (members should be educated about the role of the facilitator; focus person was unaware and unprepared for the process even though they were present at the meeting; final plan is not accessible to the focus person (too text heavy, not enough photos; graphic methods are helpful to aid understanding but this was not introduced to focus people prior to the PCP meeting; most believed the graphics didn't help the focus person understand the plan because they were not familiar with the tools used; embers say the role of the focus person as a contributed to be simply idealistic); (2) Culture (need work policy that reflects normalization, inclusion, etc; most of the facilitators were volunteers who valued community living); (3) Representation (difficult to achieve a transdisciplinary approach; most people felt that they had been underrepresented at the meeting; need to engage the non-professional participants in the plan more, especially views of family members; other residents in the hospital with ID who may have been considered friends of the focus person were not invited to the PCP plan); (4) Time (facilitators had insufficient time (reported maximum of 20 hours) to conduct the PCP process properly; - PCP needs to be a long-term intervention) Positive aspects of PCP: raised the profile of the person with ID and to give them a chance to make decisions; brought a group of people together from different backgrounds to share ideas; increased opportunities for listening and learning by creating a wider network of social support for the focus person Suggestions for improving PCP: need to educate all persons involved in a person's PCP plan about the principles and philosophy of PCP before their first meeting; educate and prepare the person with ID about PCP prior to a planning meeting; members need to develop an agreed understanding of what is meant by having the person at the centre of the plan
Limitations	Persons with ID themselves were not interviewed about the PCP process and very limited feedback from family members; evaluation of PCP mostly involved professionals.

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Martin, Ouellette-Kuntz, Cobigo and Ashworth, 2012

5	Everson, & Zhang .(2000). Person-centred planning: Characteristics, inhibitors, and supports. <i>Education and Training in Mental Retardation and Developmental Disabilities</i> , 35(1), 36-43.
Country	United Kingdom
Objectives	To explore the perspectives of individuals who use personal futures planning . More specifically, to explore what are the characteristics, inhibitors and supports that lead to successful implementation of personal futures planning.
Method	Qualitative – one focus group comprised of 9 participants who are the facilitator or primary leaders of personal centered planning circles using personal futures planning; focus group participants consisted of 4 parents, 1 friend, 1 self advocate, 1 case manager, and 2 service providers (nurse and personal care attendant); focus group was 2 hours in length
Measures	No specific coding strategies were used
Findings	<ul style="list-style-type: none"> • 4 themes emerged: (1) Evolution of person-centered planning circles or themes (they all encountered some common problems getting started with the PCP: focus person’s participation (unable or unwilling to express his/her wants and needs); circle meeting scheduling; and circle member commitment); (2) Inhibitors to the PCP process (focus person’s behaviour (aggression, inappropriate behaviours, idiosyncrasies) and lack of communication and social skills to interact with circle members and peers; circle members: schedule meetings, difficulty keeping “outsiders” other than formal service providers and parents involved; opposing views and conflict between service providers and family members slowed down the process; family members too optimistic or pessimistic about the process; problems associated with the community - interactions between the individual and the community); (3) Supports to the PCP process (when the focus person was actively participating; when circle members respect the personal and specific wants and needs of the focus person, try to understand the focus person’s dream, encourage a party or celebration to keep the focus person’s interest and need for social activities; when community members become more supportive and stay in contact with the circle); (4) Longitudinal satisfaction with PCP activities and outcomes (all participants said PCP is was a positive experience, however, most wanted a more realistic portrayal of PCP when a circle starts out- that is, that they will encounter barriers and problems along the way)
Limitations	<ul style="list-style-type: none"> • Only 1 focus group (need about 3-4 to reach theoretical saturation); • No member checks were done to obtain feedback on the themes • Selective sample • Additional research is required to more fully identify effective solutions to the barriers raised

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6	Halle, J. W., & Lowrey, K. A. (2002). Can Person-Centered Planning Be Empirically Analyzed to the Satisfaction of All Stakeholders? <i>Research & Practice for Persons with Severe Disabilities</i> , 27(4), 268-271.
Country	United States
Objectives	Invited Commentary on Holburn's (2002) position paper on how to empirically study PCP
Method	N/A
Measures	N/A
Findings	<p>Comments related to Holburn's 2002 position paper (#7 in this document)</p> <ul style="list-style-type: none"> • Agrees that empirical analysis of PCP is needed. • Disagrees with statement that PCP is being misapplied - there has been widespread adoption at various levels (e.g., agency policy, gvt regulation and law); many practices (e.g., educational practices) have been implemented without requiring empirical data to support efficacy • Argues to include other strategies used during PCP as part of the outcomes of PCP rather than as part of the process. • Measurement issues: (1) When the process and outcomes of PCP are defined and operationalized, the problem becomes will all or most of the stakeholders agree with how things are defined? Is the definition a valid a representation of the concept? Are measures capturing its essence? (2) Criticized Holburn for only suggesting behavioural theory and methodology to evaluate PCP – little rationale provided on why behavioural science methods are best suited to PCP and how they would apply to PCP; (3) outcomes of PCP were not clearly articulated, and therefore cannot choose a methodology; (4) empirical analysis can be conducted using alternative methodology that is more consistent with a value-based paradigm (e.g., democratic program evaluation, instrumental case study and qualitative methods)
Limitations	This paper does not measure the PCP process

Review of PDP Measures

Martin, Ouellette-Kuntz, Cobigo and Ashworth, 2012

7	Holburn, S. (2002). How Science Can Evaluate and Enhance Person-Centered Planning. <i>Research & Practice for Persons with Severe Disabilities</i> , 27 (4), 250-260.
Country	United States
Objectives	Position paper to make the case that PCP processes and outcomes need to be defined and measured more precisely.
Method	N/A
Measures	N/A
Findings	<ul style="list-style-type: none"> • Recommend empirical investigation of PCP, but it is suggested that PCP be categorized as an interim process that identifies desired outcomes and not as an intervention • Study Design: The traditional group method requires random assignment of participants to a treatment and control group; but random assignment may not be feasible. A single subject design may be more consistent with the individualism associated with PCP. Ideally, also use a multiple-baseline design in which the introduction of PCP is staggered across each person – then look for consistent changes in outcomes across multiple individuals following the introduction of PCP. • Require reliable implementation of the process (i.e., treatment integrity): Need to deconstruct all the components of PCP in order to verify them and observe for the occurrence or non-occurrence of them; must explain clearly and in detail what PCP entailed so that others can replicate the study • Possible measures: Assessment of Person-Centered Planning Facilitation Integrity questionnaire (Holburn, 2001a), Person-Centered Planning Facilitator Competency Scale (Green & Rollyson, 2001), or can simply ask participants themselves about the degree to which they believe various aspects of the PCP process are taking place. • Analysis: must assess the degree of adherence to the intervention being carried out; provide evaluation feedback to team members periodically about how well they are conforming to the process (feedback will likely increase integrity to the treatment) Challenges to measurement: (1) PCP is not standardized and seeks to provide individualized supports, its methods are meant to adapt to the changing need, goals and circumstances of the focus person; (2) PCP has multiple components and thus treatment integrity is difficult to measure; (3) Difficult to define and measure the more subjective aspects of PCP (e.g., shared appreciation of the desires of the focus person); (4) Are the “other” strategies generated by the PCP meeting also evaluated as part of the PCP intervention? (e.g., positive behaviour support strategies); (5) hard to tease apart other components when a variety of strategies are being used as part of PCP.
Limitations	Critiques/comments on this paper are provided in #13 below.

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8	Holburn, Jacobson, Schwartz, Flory, & Vietze (2004). The Willowbrook futures project: A longitudinal analysis of person-centered planning. <i>American Journal on Mental Retardation</i> , 109(1), 63-76.
Country	United States
Objectives	To determine the efficacy and long-term effects of PCP
Method	<ul style="list-style-type: none"> • Quantitative: Longitudinal analysis • N=38 residents living at 4 institutions in New York City; Matched control design: 20 received PCP and 18 received conventional individual service planning (matching on residence, age, ID level, presence of psychiatric disorders, and overall severity of challenging behaviour) • Procedure: Each participant had their own team which was led by a facilitator; facilitators were all trained in "Personal Futures Planning" by Mount (1992); PCP meetings were held once per month; Control group: teams met 4 times per year • Analysis: Averaged responses across team members. Items combined to form subscales to form process and outcome indices. • Generalized estimating equation (GEE) models were used to evaluate trends in process and outcomes for both groups
Measures	<ul style="list-style-type: none"> • Measures: Personal Futures Planning Indicators; Indicators of Principles Scale; Person-Centered Planning Quality of Life Indicators (process and outcome subscales generated from the 3 scales). <ul style="list-style-type: none"> ○ Process Index subscales: strategic roles; personal relationship with the focus person; desire for change; creation of a personalized vision; commitment to planning and follow-up; flexible funding and resources ○ Outcome Index subscales: Autonomy & choice making; home, work & day activities; health; relationships; community places; respect; competence; satisfaction.
Findings	<ul style="list-style-type: none"> • Rate of improvement in the intervention group (PCP) was significantly better than the control group (ISP) for both process and outcome measures. Specifically, autonomy, choice-making, daily activities, relationships, and satisfaction improved.
Limitations	<ul style="list-style-type: none"> • PCP facilitators received ongoing support and consultation from Dr. Mount throughout the project (unrealistic amount of support) • Intervention group received extra attention and time to implement • Some of the staff served on both intervention and control teams – so differences between planning approaches could have been reduced (e.g., ISP teams could have adopted some of the PCP planning philosophy or procedure due to some staff having exposure to new method). • Proxy data was used for both process and outcome due to the fact that participants were cognitively impaired to fill out questionnaires themselves. • Extra funds were provided to the PCP group for community transition and activities. Greater access and activity involvement could have explained group differences in outcomes.

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9	Holburn, S., Jacobson, J. W., Vietze, P. M., Schwartz, A. A., & Sersen, E. (2000). Quantifying the process and outcomes of person-centered planning. <i>American Journal on Mental Retardation</i> , 105(5), 402-416.
Country	United States
Study Objective(s)	The development of three instruments to measure both the processes and outcomes of person-centered planning
Method	<ul style="list-style-type: none"> Quantitative approach; N=approximately 200 participants 5 phases: (1) Pool of items from multiple sources; (2) Items classified by experts into Process Index and Outcome Index; (3) Items sorted into categories in a way that maximized inter-rater agreement (process only, primarily process item and secondarily an outcome item, outcome only, and primarily outcome item and secondarily a process item); (4) Examined reliability of the two indices (test-retest; internal consistency); and (5) Examined data.
Measures	Instrument development based on pool of items
Findings	<p>3 INSTRUMENTS DEVELOPED:</p> <ul style="list-style-type: none"> Indicators of Principles Scale - assess adherence to 8 standards of PCP; 25 multiple choice questions (services and supports derive from person's preferences, interests, and capacities; person and important others are involved in planning; person makes choices and decisions based on experience; activities and services foster inclusion, respect, relationships; person uses natural community supports; planning is collaborative and recurring; opportunities, experiences, and flexibility are maximized; person is satisfied with services and supports). Person-Centered Planning Quality of Life Indicators - assesses 8 areas of quality of life (community places, autonomy & choice-making, health, relationships, work/day activities, competence, respect, quality of home environment), using 40 multiple choice questions Personal Futures Planning Indicators - 12 items on presence of 12 process factors related to positive outcomes in PCP (desire for change from at least 1 team member, a skilled facilitator, a positive view of personal capacities (team members focus on person's strengths and work to support them), a committed champion (a person who is committed to act on behalf of the person in helping), a personal plan that has details about enhancing the person's community involvement, a community builder (a team member who links to community resources and people to create opportunities), connections to a wider community, an agency committed to change for individualized support, access to decision makers, resources to ensure individualized support (time and money), a support circle, and regular meetings to review progress). Process Index (20 items) into (1) presence of strategic roles, (2) Personal relationship with focus person, (3) Desire for change, (4) Creation of personalized vision, (5) Commitment to planning & follow-up, (6) Flexible funding/resources Outcome Index (51 items) into: (1) Autonomy/Choice making, (2) Home, (3) Work/day activities, (4) Health, (5) Relationships, (6) Community places, (7) Respect, (8) Competence, (9) Satisfaction Reliability is $r=.88$ for Process Index and $.94$ for the Outcome Index; Cronbach's alpha was $.87$ for the Process Index and $.97$ for the Outcome Index Confirmatory Analysis: strong positive association between Process Index and Outcome Index (overall: $r=.69$, $p < .01$; range $r=.41$ to $r=.78$) (process items predict about half of outcomes); 2 primary and 1 secondary factor identified (suggests considerable overlap between the 2 concepts); correlation between the factors and expert opinion $r=.71$
Limitations	<ul style="list-style-type: none"> Categorizing Process Index items had poorer agreement among raters than the Outcome Index; Small sample size; interpret factor analysis results with caution Outcome Index does not measure all outcomes of PCP; focus on QoL, not on changes in organizational practices and structure. No threshold score from the Process Index that indicates whether PCP is taking place

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10	Lotan & Ells (2010). Adults with intellectual and developmental disabilities and participation in decision making: Ethical considerations for professional-client practice. <i>Intellectual and Developmental Disabilities</i> , 48(2), 112-125.
Country	Canada
Study Objective(s)	The primary aim is to examine the assumptions about concepts related to decision making and the PCP process. Second, to offer practical strategies to involve persons with ID in the decision-making process; philosophical principles underlying PCP and person directed decision making.
Method	Theoretical Paper
Measures	N/A
Findings	<p>Authors propose professionals adopt a moral principle or respect for persons as an overarching principle.</p> <ul style="list-style-type: none"> • Autonomy: assessed on a decision-specific basis; it is through interaction with others in a supportive environment that skills are learned and confidence is gained for autonomy; foster autonomy in others by creating the right conditions. • Empowerment: an individual acts in ways that encourage others to advocate for their own needs and preferences; can only occur in the context of specific types of relationships • Participation in Decision-Making; medical research suggests that individuals want information-both good and bad, and about all aspects of the problem and options for interventions; gap between the desire for information and the wish to actually make medical decisions; exercising one's autonomy in decision making includes being able to decide how, how and how much one wants and needs to be involved in actually making the decisions as well as what information one needs and who will make those decisions. • Asymmetrical Power and Outer-Directedness: refers to when a person possesses or is believed to possess something that is of significance to the other person and that the other person can only obtain from this primary person; Includes information, expertise, and access to key persons and to material objects (money); person must trust the professional; professionals must carefully assess voluntariness when they ask persons with ID (must consider the value of beneficence and nonmaleficence in their involvement and weight interventions); Outer-directedness: individuals with ID tend to use external cues in a harmful and indiscriminate manner and not rely on their own internal problem solving strategies. • Propose Overall working Principle of Respect for persons: it is an overarching value-this encompasses all the concepts and values discussed above; "respect for persons" is an attitude toward persons based on the premise that "they are a thing valuable in itself"; provide a set a practical considerations to operationalize the principle of respect of persons. • Step-wise approach to decision making: (1) Identify the objectives; (2) Assess factors that contribute to meaningful participation; (3) Prepare conversations with the client; (4) Follow-up with the client and team • Table 1 in article provides excellent examples of how to operationalize respect and other values that are linked to PCP and decision-making.
Limitations	This paper does not measure the PCP process

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11	Mansell, J. & Beadle-Brown, J. (2004). Person-centred planning or person-centred action? Policy and practice in intellectual disability services. <i>Journal of Applied Research in Intellectual Disabilities</i> , 17, 1-9.
Country	United Kingdom
Objectives	How to improve PCP services in Britain
Method	Synthesis of the literature on PCP, individual planning, and British service context.
Measures	N/A
Findings	<ul style="list-style-type: none"> • Challenges of implementing PCP: (1) many individuals with ID have very severe problems that affect their participation in planning; (2) extent to which individuals can understand choices and decisions is limited; (3) nature of difficulties may strain relationships with staff and as a result staff have difficulty empathizing with the individual or to believe that things can change; (4) - social networks of persons with ID are sometimes limited or non-existent – building a ‘circle of support’ can be extremely challenging to make PCP work; (5) individuals have difficulty with reciprocity in relationships that is a core characteristics of sustaining helping relationships • Evidence base for the effectiveness of PCP is weak compared to other approaches • In Britain: (1) individual planning seems to only reach a minority of service users; (2) are often a paper exercise (have a plan that is not used) • Large scale evaluations show that individual plans are not connected to the real lives of people using services; goals set without presence of person and their family members; long-term goals were omitted; goals and objectives not written in measurable terms • Staff training: (1) should be in context of supporting people on site; (2) helping individuals to gain skills, be empowerment; (3) focus on facilitating tangible change in the lives of people instead of on the planning part (having meetings and making plans should not be the outcome and sole activity of PCP)
Limitations	This paper does not measure the PCP process; see comments/critiques in #14, 20

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12	Mansell, J. & Beadle-Brown. (2004). Person-centred planning or person-centred action? A response to the commentaries. <i>Journal of Applied Research in Intellectual Disabilities</i> , 17, 31-35.
Country	United Kingdom
Objectives	Commentary and Clarification of their points made in their original article (see original article summary above, #11; critiques in #14 and #20)
Method	N/A
Measures	N/A
Findings	<p>Comments:</p> <ul style="list-style-type: none"> • Scale of Task (Implementing PCP according to the White Paper Valuing People): suggest incremental approach to PCP implementation • Feasibility and effectiveness of individual planning • There is evidence for the effectiveness of individual planning in studies that look at active support, positive behaviour support, and individualized service provision. However, evidence base is still limited. • No studies on large scale implementation • Argues PCP is one part of a complex intervention • It is possible that specific individualized services such as active support can be more effective than individualized planning; it's all about how staff act and assist persons and not so much about the planning process • Concern Valuing People just offers a new model of planning things and that little will change in terms of outcomes • Achieving person-centred action • Concern that PCP will only promote meetings, forms, and training but little in terms of changing staff practices (referred to as the "activity trap"). • Planning & action are different things and the risk of no action is the greatest concern; connection between is uncertain • Argues that changing the form of individual planning is going to have little effect on the lives of people with ID; the question is what are the best ways to enhance a person's life with ID in terms of actions/things to do. • Agree with O'Brien that need to continually question the results of PCP in everyday life in order to inform the process of change.
Limitations	This paper does not measure the PCP process

Review of PDP Measures

Martin, Ouellette-Kuntz, Cobigo and Ashworth, 2012

13	O'Brien, J. (2002). Person-Centered Planning as a Contributing Factor in Organizational and Social Change. <i>Research & Practice for Persons with Severe Disabilities</i> , 27(4), 261-264.
Country	United States
Objectives	Invited Commentary on Holburn's (2002) position paper (see #7 above)
Method	N/A
Measures	N/A
Findings	<p>Comments:</p> <ul style="list-style-type: none"> • Outcomes need to measure PCP values: autonomy, inclusion, meaningful relationships, contribution and respect. • Disagrees with Holburn's understanding of PCP: While Holburn wants to operationalize interventions and objectively measure their outcomes, O'Brien defines PCP as a way to mobilize action to change the way services support a person with ID, and suggests that PCP is worthwhile in its own right and not because it achieves particular quality of life goals. • The impact of PCP is imperfect, but it does make a difference – the difference it makes has nothing to do with statistical significance. One can ask the focus persons or their families how their life has changed since the implementation of PCP, or witness it firsthand • Argues an over-focus on the methods of PCP detracts from its central question – i.e., how will practices change to enable the focus person to have a life that is meaningful • Argues PCP may not be the cause of changes in a person's life but a way of getting support people to working together to enable the person to live the best possible life.
Limitations	This paper does not measure the PCP process

Review of PDP Measures

Martin, Ouellette-Kuntz, Cobigo and Ashworth, 2012

14	O'Brien, J. If person-centred planning did not exist, Valuing People would require its invention (2004). <i>Journal of Applied Research in Intellectual Disabilities</i> , 17, 11-15.
Country	United States
Objectives	Invited Commentary of Mansell & Beadle-Brown (2004) position paper (#11 above)
Method	N/A
Measures	N/A
Findings	<p>Comments:</p> <ul style="list-style-type: none"> • PCP is only one aspect of the strategy to change services for individuals with ID; also involves mainstream resources, specialist services and citizens • Choice is most important value to allow people to decide how they want to live/be supported • Disagrees that reciprocity is an issue of carrying out PCP plans with persons with ID. • PCP is: (1) one medium for creating positive change; (2) can lead to benefits even without successful large-scale change; (3) at the individual level, can make changes in a person's day to day life through "emergent change" (i.e., results of repeated, shared, and sustained experiments by small groups who learn to improve situations) • PCP failure: (1) is increased with cynicism and when people are not fully committed; (2) due to mainstream and specialist services not changing • Call for deeper commitment to PCP and continued critical thinking of how it works or doesn't work in everyday life
Limitations	This paper does not measure the PCP process

Review of PDP Measures

Martin, Ouellette-Kuntz, Cobigo and Ashworth, 2012

15	Renzaglia, A., Karvonen, M., Drasgow, E., & Stoxen, C.C. (2003). Promoting a lifetime of inclusion. Focus on Autism and Other Developmental Disabilities, 18(3), 140-149.
Country	United States
Objectives	Explain the conditions and practices that foster inclusion for persons with disabilities. More specifically, they explain the strategies of universal design, person-centered planning, self-determination, and positive behaviour support.
Method	Synthesis of the literature.
Measures	N/A
Findings	<ul style="list-style-type: none"> • Universal Design: refers to the creation of buildings or environments that accommodate the universe of potential users. In other words, design programs and environments for the divergent needs of those with disabilities so that everyone can use them. Examples include computer assisted instruction, cooperative learning, hands-on learning, etc. Other examples include, bringing job coaches or other paid helpers to support individuals with disabilities in employment settings. • PCP Checklist: (1) Were participants selected by the person and by his or her family?; (2) Is the plan based on the persons' dreams?; (3) Are the services chosen to meet the goals based on the individual, regardless of whether the services already exist?; (4) Is the plan used to create the person's Individualized Education Plan (IEP), Individual Transition Plan (ITP), or Individual Habilitation Plan (IHP)? • Other points about PCP: (1) Collaboration of the individual with significant others in identifying desired outcomes and problem solving how these outcomes might be achieved; (2) Planning process should culminate with an action plan; (3) Implement action plan; (4) Action plan should be revisited and revised, if appropriate, on a regular basis; (5) Process should improve quality of life by increasing choice, skills, and involvement in inclusive environments • Ecological Inventory & Analysis: ecological inventory of an individual's priorities for skill development and supports should be conducted after PCP; • Self-Determination: refers to the skills, knowledge, and beliefs that enable a person to engage in goal-directed, self-regulated, autonomous behaviour; essential components of self-determining behaviour include: choice making skills; decision-making skills; problem solving skills; goal setting and attainment skills; self-observation; self-evaluation; self-reinforcement skills; self-instruction skills, self-advocacy and leadership skills; an internal locus of control; positive attributions of efficacy and outcome expectancy; self-awareness; and self knowledge; <ul style="list-style-type: none"> ○ Instruments have been developed to assess self-determination: The Self-Determination Knowledge Scale, The Arc Self-Determination Scale, ChoiceMaker Self Determination Assessment, Minnesota Self-Determination Scales, AIR Self-Determination Scale. ○ Can also measure self-determination through task analysis. Calculate the percentage of steps completed correctly and independently to determine how well the person has learned to use that particular skill. • Positive Behaviour Support: includes functional assessment and comprehensive, multicomponent interventions; movement away from punishment based approaches and towards instruction that emphasizes functional skill development.
Limitations	Mainly concepts and philosophical ideas presented than strategies.

Review of PDP Measures

Martin, Ouellette-Kuntz, Cobigo and Ashworth, 2012

16	Robertson, Emerson, Krinjen-Kemp, Towers, Romeo & Knapp et al. (2006). Longitudinal analysis of the impact and cost of person-centered planning for people with intellectual disabilities in England. <i>American Journal on Mental Retardation</i> , 111(6), 400-416.
Country	England
Objectives	To determine the efficacy, direct and indirect costs of PCP
Method	<ul style="list-style-type: none"> Quantitative; N=93 adults (ages 16 to 86) Non-parametric tests were used for all comparisons (Wilcoxon; McNemar's) Information on participants was collected every 3-6 months for approximately 2 years
Measures	<ul style="list-style-type: none"> Background information: Adaptive Behavior Scale –Residential and Community (part 1); PAS-ADD Checklist; Learning Disabilities Casemix Scale; English Indices Deprivation Direct costs: time spent by the trainer, average number of hours staff spent, and roles/professions of staff members; costs for resources associated with the training (i.e., salary, insurance and pension contributions within each salary; stationary, catering, renting a facility. Note transportation costs were not included. From these, calculate cost per trainee of attending PCP training (averages also calculated) Indirect costs: comprehension package of support for each participant was calculated or estimated using a variety of methods. Use of the Residential Services Setting Questionnaire was used. For staffing levels. Accommodation costs were calculated based on 4 pieces of information: direct staffing, non-staffing costs (heat), administrative or professional staff working across the whole site, and central office overheads. Every 3 months: Health Survey for England; Index of Community Involvement; Social Network Map; Client Service Receipt Inventory Every 6 months: Strengths and Difficulties Questionnaire, Risks Scale, Changes in the level of choice experienced by the participants
Findings	<ul style="list-style-type: none"> Analysis on two rounds of baseline data showed no significant differences for any of the outcomes measures; Analysis on three rounds of baseline data showed 3 significant differences out of a total of 72 comparisons (i.e., increase in the total number of activities, variety of activities, and total number of visits with friends). Comparisons between baseline and final data points found that PCP was associated with significant change on 11 outcome variables: 52% increase in the size of social networks, 2.4 times greater chance of having active contact with family, 40% increase in level of contact with friends, 2.2 times greater chance of having active contact with friends, 30% increase in number of activities, 25% increase in the variety of activities, 33% increase in hours per week of scheduled day activities, and 2.8 times greater chance of having more choice. <ul style="list-style-type: none"> Negative direction findings: Significant increase in hyperactivity scores and number of reported health problems by a key informant. No significant effects found for: hospital-based services, employment, physical activity, medication Conclusion: PCP benefits some domains but not all – e.g., benefits in the number and variety of community-based and non-inclusive activities but less or no change in outcomes related to social inclusion.
Limitations	<ul style="list-style-type: none"> Many statistical analyses were conducted but did not correct for multiple statistical comparisons; not enough power (small sample size) Evaluates short-term impact of PCP (over maximum of 2 years); certain quality of life outcomes take longer to develop (e.g., social relationships, employment) Selection bias: only agencies who were extremely motivated to implement PCP

Review of PDP Measures

Martin, Ouellette-Kuntz, Cobigo and Ashworth, 2012

17	Robertson, Emerson, Krinjen-Kemp, Towers, Romeo & Knapp et al. (2007). Person-centered planning: factors associated with successful outcomes for people with intellectual disabilities. <i>Journal of Intellectual Disability Research</i> , 51(3), 232-243.
Country	England
Objectives	To determine what factors are associated with (1) probability of receiving a PCP, (2) and improvements in the areas (social networks; contact with family; contact with friends; community-based activities; scheduled day activities; and choice) as a result of PCP
Method	<ul style="list-style-type: none"> • Quantitative; N=93 adults with ID (ages 16 to 86) from 4 different areas of England. • Consultants with PCP implementation; training took 20 days or 84 hours - provided to facilitators and managers. • Data collection every 3-6 months for 2 years • Chi-squared tests; Mann-Whitney tests; stepwise multivariate logistic modelling
Measures	<ul style="list-style-type: none"> • Background information on the participants was collected using the following measures: Adaptive Behavior Scale, Psychiatric Assessment Schedule for Adults with Developmental Disabilities, syndromes associated with ID; Learning Disabilities Casemix Scale (challenging behaviour), residential history, existing arrangements for individual planning, and the English Index of Multiple Deprivation. • Every 3 months: current scheduled activities, physical activities, items from the Health Survey for England; community involvement using the Index of Community Involvement; social networks using the Social Network Map; contact with family and friends, use of hospital services; health checks; community-based service receipt with the Client Service Receipt Inventory; and PCP activities • Every 6 months: health problems, medications, the person's behavioural and emotional profile, using the Strengths and Difficulties Questionnaire, the Risks Scale (accidents, risks, injuries), and changes in the level of choice. • If informal helper was available, information was collected on them every 6 months: staff support and professional input in the home, satisfaction with current arrangements, involvement in planning, barriers to meeting the participant's goals, impact of PCP on the person. • -information was collected on the PCP facilitators every 6 months: demographic characteristics; reported impact of PCP on participant; barriers to goals; commitment to PCP; and perceived self-efficacy.
Findings	<ul style="list-style-type: none"> • 70% (n=65) of participants had a PCP that was developed and maintained • Variables associated with PCP: (1) being involved in the study for longer and having a key worker at baseline (2) having a facilitator with a high personal commitment to PCP (12 times more likely to receive a PCP); (3) mental health disorders, emotional and behavioural problems, autism, and those with more health problems were less likely to receive a PCP plan • Overall findings: abilities of participants was not associated with outcomes of PCP with the exception of having increased contact with friends
Limitations	Does not measure PDP process; look at outcomes

Review of PDP Measures

Martin, Ouellette-Kuntz, Cobigo and Ashworth, 2012

18	Rudkin, & Rowe.(1999).A systematic review of the evidence base for lifestyle planning in adults with learning disabilities: implications for other disabled populations. <i>Clinical Rehabilitation</i> , 13, 363-372.
Country	England
Objectives	Perform a systematic review of the evidence base for lifestyle planning for adults; effectiveness of PCP and its outcomes
Method	<ul style="list-style-type: none"> • Literature review and Synthesis of both quantitative and Qualitative articles on lifestyle planning in adults with DD/Learning Disability. • Systematic search of electronic databases (Medline, PsychLit, Embase, and Cinahl) from years 1974 to 1998. A search of the Cochrane database was also done. Hand-searching of 4 journals was also carried out (BILD Bulletin, Journal of Intellectual Disability Research, Journal of Applied Research in Intellectual Disabilities, and Tizard Learning Disability Review. • Eligibility criteria: original data regarding lifestyle planning in a learning disability population.
Measures	N/A
Findings	<ul style="list-style-type: none"> • No published randomized controlled trials have been done; 1 controlled trial found (Factor et al) that showed significant increase in knowledge of PCP, client participation in individual service plans, some types of leisure participation (i.e., volunteer activities; but lower levels of life satisfaction was reported in the intervention group (likely clients have been made more aware of possibilities) • Only 5 articles on lifestyle planning contain outcome data involving 108 participants in total; no common outcome measures used so not possible to do a meta-analysis. • Another study found that PCP develops plans that are more client centered than non-PCP approaches of lifestyle planning. • A third study found that a care management approach instead of a traditional approach to community resettlement may be less effective • A fourth resource management study found that more responsibility should be delegated to local rather than central managers to promote PCP (very little outcome data) • The fifth study examined shared action planning with both staff and clients and found that only 50% (6 of 12 clients) remembered the content of the training (no outcome data). • Overall, the evidence base is weak!
Limitations	Does not measure the PDP process

Review of PDP Measures

Martin, Ouellette-Kuntz, Cobigo and Ashworth, 2012

19	Smith, A. (2007). Evaluating personalized services. <i>Journal of Integrated Care</i> , 15(2), 41-48.
Country	Scotland
Objectives	To audit organizations to find out what makes personalized support services work well
Method	<ul style="list-style-type: none"> • Qualitative; gathered information through semi-structured interviews, group work, and “just being with people who use the service” • Used “process work” and “complexity theory” strategies to collect and make sense of the information regarding organizations • 4 organizations
Measures	<ul style="list-style-type: none"> • Used the “Five Dimensions” tool and process to gain information about the support being delivered in organizations; each Dimension has sub-dimensions (See Figure 1 in paper); tool described as a “reflexive and phenomenological process”; dimensions include: (1) Uniqueness and Diversity; (2) Power; (3) Right Relationship; (4) Developing, Learning and Growing; and (5) Usefulness and Relevance • Information was gathered from Team members who came from diverse experiences (people with ID, consultants, direct support staff, managers, etc)
Findings	<p>6 themes emerged:</p> <ol style="list-style-type: none"> 1) Personalization must occur throughout the organizations, not just at the point of delivery of service – if not, there is incongruity between how people who receive the services are being treated and how staff members experience power relationships. 2) Limit the size of the organization – leaders of the organization should know the persons they serve and be on personal terms with staff, the focus person, and other stakeholders; organizations splitting its operations into divisions to maintain personalized care 3) Person and their team need to have control of and sense of finances – the more control and greater the transparency, the more creative and personalized the services become for each individual 4) Quality of the relationship between the main supports and the focus person is crucial – staff should be matched carefully to work with the individual person 5) Regular review and strengthening of the value based to combat dominant beliefs and views in society – constant reiteration of beliefs and what it means to provide personalized services throughout the organization is required 6) Awareness of feedback loops between levels of the organization – good quality relationships translates to staff being able to challenge others within and outside the organization; this led to demand for more unique and personalize services for individuals because of staff being able to be innovative.
Limitations	<ul style="list-style-type: none"> • Poor article, written in colloquial form • Quality of qualitative methods was poor • Five Dimensions Tool is more a summary of the values of PCP; it is not a validated tool • Number of participants is unclear

Review of PDP Measures

Martin, Ouellette-Kuntz, Cobigo and Ashworth, 2012

20	Towell, D. & Sanderson, H. (2004). Person-centred planning in its strategic context: Reframing the Mansell/Beadle-Brown Critique. <i>Journal of Applied Research in Intellectual Disabilities</i> , 17, 17-21.
Country	United Kingdom
Objectives	Invited Commentary of Mansell & Beadle-Brown (2004) position paper (see #11 above)
Method	N/A
Measures	N/A
Findings	Comments: <ul style="list-style-type: none">• Effective National Implementation in UK will need to: (1) promote role of self-advocates and families in leading PCP; (2) emphasize quality instead of quantity which aim to achieve impact not just develop plans; (3) secure inclusion in mainstream services; (4) invest in training to improve PCP and wider cultural change in service organizations; (5) develop partnerships to create mainstream service and community changes for inclusion and greater opportunities for persons with ID
Limitations	Does not measure the PDP process

Appendix B: Linking Existing Scales to Proposed Core Elements of PDP

Core elements	Indicators of Principles Scale	Personal Futures Planning	Process Index	Facilitation Integrity	Team Integrity
The person is involved in selecting the timing and location of the meeting	--	--	--	1. Date and time of the meeting was convenient for the person	--
The person chooses who is involved	6. The person’s planning team includes family and friends, independent advocates or staff who know and care about the person 11. The team includes family members, neighbours, friends, co-workers and other natural support in the person’s activities and relationships	4. A Circle of Support. A support circle has been formed that consists of people who care and who give their time voluntarily. It is diverse group of people that does not consist entirely of human-service workers.	Includes items #6 and #11 from Indicators of Principles Scale	6. Attempts were made to get relevant people at the meeting, including timely notification and, if feasible, transportation assistance.	--
The person is involved in discussions	5. The person and those who know him or her best participate in meetings where important plans are formulated and decisions made. 22. The full range of quality of life issues associated with major lifestyle decisions at each meeting with the person and his or her representatives	--	Includes items #5 and #22 from Indicators of Principles Scale	20. All persons gave input during the meeting	4. Were respectful of the person. 10. Kept discussion centered on the person rather than each other or the agency.

Review of PDP Measures

Martin, Ouellette-Kuntz, Cobigo and Ashworth, 2012

Core elements	Indicators of Principles Scale	Personal Futures Planning	Process Index	Facilitation Integrity	Team Integrity
The person has the opportunity to make meaningful choices	<p>7. The person is assisted to experience and understand the alternatives before making choices</p> <p>8. Important choices about home, work, and relationships are made by the person to the extent possible and with the necessary assistance.</p> <p>19. The person or those who know him or her best make decisions about both major and minor uses of resources and funding</p>	--	Includes items #7, #8, and #19 from Indicators of Principles Scale	--	8. Promoted decision making by the person
The person's natural supports are encouraged to participate in discussions	5. The person and those who know him or her best participate in meetings where important plans are formulated and decisions made.	5. A Skilled Facilitator. A facilitator guides the group in developing a common vision for the person. The facilitator is a good listener and encourages participation of all group members. After the initial plan is developed, the facilitator comes to follow-along meetings.	Includes item #5 from Indicators of Principles Scale, and #5 from Personal Futures Planning	<p>17. The facilitator gave positive feedback to participants when they shared information.</p> <p>20. All persons gave input during the meeting</p>	--
There is trust among the members of the planning team	--	--	--	--	7. Listened attentively to other team members

Review of PDP Measures

Martin, Ouellette-Kuntz, Cobigo and Ashworth, 2012

Core elements	Indicators of Principles Scale	Personal Futures Planning	Process Index	Facilitation Integrity	Team Integrity
The team works collaboratively and with respect	--	1.Desire for Change. The focus person, or someone who cares about the person, wants things to change. There is an interest that leads to voluntary commitment to work together.	Includes item #1 from Personal Futures Planning	14.The facilitator encouraged creative problem-solving. 16.The facilitator obtained consensus in problem solving.	3. Suggested solutions to problems. 6. Considered others' opinions. 7. Listened attentively to other team members
Focuses on the person's strengths, abilities, and aspirations	1. Team minutes focus on interests, preferences, strengths, and capabilities. Planning for the person's daily activities and support needs is based on vision, preferences, and capacities.	2. Positive View of Personal Capacities. The group is able to understand the person in a way that emphasizes his or her capabilities and potential, and the group recognizes and uses their own capacity as individuals.	Includes item #1 from Indicators of Principles Scale, and #2 from Personal Futures Planning	10.The facilitator kept the discussion centered on the interests and desires of the person. 11.The facilitator was oriented more toward building capacity than toward correcting deficiencies.	9. Honored the person's preferences and choices. 11. Were not negative in their expectations of the person.
Identifies clear actions to achieve the goals in the plan	4a) the person or those who know him or her best select goals 4b) progress toward goals is measured objectively 4c) goals are achieved How many of these elements are typically part of the individual planning process for this person?	--	Includes items 4a-c from Indicators of Principles Scale	19. Strategies and responsibilities for follow-up were made clear. 21. The plan of action is summarized at the end of the meeting.	--

Review of PDP Measures

Martin, Ouellette-Kuntz, Cobigo and Ashworth, 2012

Core elements	Indicators of Principles Scale	Personal Futures Planning	Process Index	Facilitation Integrity	Team Integrity
Identifies supports within and beyond those of the provider agency that are needed to achieve the goals in the plan	3. Services and supports are individualized and directly related to functional outcomes selected by the person, if possible, or those who know him or her best.	11. Flexible Resources for Personal Support. Small amounts of time and money are available to do creative things that meet needs identified by the support circle.	--	15. If present system constraints prevented achievement of the person's wish(es), then alternative ways of achievement were discussed.	--
The person's services, supports, and day-to-day activities are adapted to ensure that they are in sync with the goals identified in the plan	18. Funding has been tailored to support an individualized service plan and is flexible enough to allow for changes in what is needed and desired.	--	Includes item #18 from Indicators of Principles Scale	15.If present system constraints prevented achievement of the person's wish(es), then alternative ways of achievement were discussed.	--
Periodic evaluation of actions and outcomes	4b) progress toward goals is measured objectively	12. A Productive Ongoing Process. The team meets on a regular basis to review the person's status, follow-up on action steps, and work productively to make the vision become a reality.	Includes item #4b from Indicators of Principles Scale, and #12 from Personal Futures Planning	8.Team progress is reviewed early in the meeting, including status of pending action steps	--
Ongoing commitment to revisiting actions and outcomes	23a) Attendees at meetings are committed to supporting the person 23b) at least some attendees are unpaid 23c) attendance is stable How many of these elements are part of the individual planning process for this person?	6. A Committed Champion. There is a person on the team who has a personal relationship that transcends legal requirements, rules, and a sense of social justice. A champion is not simply an advocate. A champion is there for the person for the long haul, and does not "leave the scene" when the problem has been solved.	Includes item #23a-c from Indicators of Principles Scale, and #6 from Personal Futures Planning	Team progress is reviewed early in the meeting, including status of pending action steps	12. Followed through with commitments made in the previous meeting.

Review of PDP Measures

Martin, Ouellette-Kuntz, Cobigo and Ashworth, 2012

Core elements	Indicators of Principles Scale	Personal Futures Planning	Process Index	Facilitation Integrity	Team Integrity
<p>The person is happy or satisfied with progress made toward identified goals</p>	<p>24. The person has frequent opportunities to express satisfactions with his or her relationships, home, and daily routines and a record is kept.</p> <p>25. Lifestyle aspects with which the person is dissatisfied are investigated and appropriate, tangible, positive changes are pursued.</p>	<p>--</p>	<p>Includes items #24 and #25 from Indicators of Principles Scale</p>	<p>--</p>	<p>--</p>